

Genomics and Newborn Screening Program 2023



INSTEP Monthly Summary Reporting Quick Guide



Indiana
Department
of
Health





This guide serves as a supplemental resource to the [Indiana INSTEP Monthly Summary Reporting \(MSR\) Training \(Course ID 1095938\)](#). All staff must take this online training before beginning to enter any heel stick or pulse oximetry (CCHD screen) information into INSTEP.

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Questions about Monthly Summary Reporting (MSR)?

For help with heel stick and pulse oximetry MSR access, MSR entry or other follow-up needs, contact the Newborn Screening Reporting Coordinator:

Newborn Screening Reporting Coordinator

Phone: 317-233-7019

Email: NewbornScreening@health.in.gov

Fax: 317-234-2995

Other questions about newborn screening?

Contact the Genomics and Newborn Screening Program with questions about heel stick or CCHD screening. Contact the Early Hearing Detection and Intervention Program with questions about the hearing screen.

Genomics and Newborn Screening Program

NewbornScreening@health.in.gov

Phone: 888-815-0006

www.nbs.in.gov

Early Hearing Detection and Intervention (EHDI) Program

Hearing screen MSR (EARS) and follow-up information can be found online at www.hearing.in.gov

Heel Stick Exception Types

Transfer Out Without Screen:



Use when the infant transfers out of your facility before the initial heel stick.

Review the [Transfer Out section](#) to see all information that must be included.

Transfused:



Use if the infant did not have a heel stick screen performed before receiving a blood transfusion

Finally Screened:



Use when the infant that was previously an exception has had their screen.

Include the **date**, **time**, and **location** and whether the **result was normal or abnormal** for all heel sticks performed **outside of Indiana**.

Deceased:



Use when the infant has passed away prior to collecting an initial heel stick.

Always provide the date and time of death in the notes section.

Religious Refusal:



Use when a family refuses the heel stick due to religious reasons.

Upload a completed and signed Religious Waiver in a Religious Refusal exception immediately.

Ensure the waiver is the **most current version**. Outdated waivers will not be accepted.

Discharged Home Without Screening:



Use only if an infant is **inadvertently discharged** from your facility before an initial heel stick.

1. Alert GNBS by phone at 888-815-0006 **immediately**.
2. Submit this exception in INSTEP immediately.
3. Document all supporting details within the MSR notes section to assist with follow-up.

NOTE: Infants in hospice care still need a heel stick.

Infants on palliative/hospice care are NOT exempt from receiving the heel stick.

If the family wishes to refuse the heel stick, the religious refusal process must be followed.

Pulse Oximetry (CCHD) Exception Types



Transfer Out Without Screen:

Use when an infant transfers out of your facility before a pulse oximetry is performed.
Review the [Transfer Out section](#) for more information.



Echo Prior to Pulse Oximetry (CCHD) Screening:

Use when the infant will not have pulse oximetry (CCHD) screening performed because they had an echocardiogram performed prenatally or before 48 hours after birth.



Supplemental Oxygen (O₂) / Respiratory Support:

Use when an infant will not have pulse oximetry performed due to being on supplemental O₂ or other respiratory support.
It is up to the attending physician to decide whether screening will occur once the infant is removed from respiratory support. See the [Supplemental O₂ section](#) to learn more.



Finally Screened:

Use when an infant was previously entered as an exception and has CCHD screening and/or an echocardiogram performed, which includes if a screen was performed at an out of state facility after an infant was entered as a transfer out without screen.

Include the **date, time, and location performed**, as well as the **oxygen saturations of right hand and one foot** and/or whether the **echocardiogram results** were normal or abnormal.



Deceased/Hospice Care:

Infants in hospice care **may be exempt** from CCHD screening.

The option for screening should always be discussed with the family.

1. Use this exception if the family does not want the infant to be screened.
2. Enter the **date and time of death** or **date when discharged to hospice**.



Religious Refusal:

Use when a family refuses the CCHD screen due to religious reasons.

Upload a completed and signed Religious Waiver in a Religious Refusal exception immediately.
Ensure the waiver is the [most current version](#). Outdated waivers will not be accepted.



Discharged Home Without Screening:

Use only if an infant is **inadvertently discharged** from your facility before CCHD Screening.

1. Alert GNBS by phone at 888-815-0006 **immediately**.
2. Submit this exception in INSTEP immediately.
3. Document all supporting details within the MSR notes section to assist with follow-up.



Prenatally Diagnosed with CCHD:

Use when an infant will not be screened because they were diagnosed with a critical congenital heart defect (CCHD) prenatally.



If infant is on supplemental oxygen and will REMAIN in the birth facility:

Birth facility reports infant as "Supplemental Oxygen/Respiratory Support" MSR exception.

Infant is removed from O₂ and screened for CCHD:

Birth facility enters as "Finally Screened" MSR exception and includes the O₂ scores.

NBS Reporting Coordinator will review scores and close the case.

Infant is removed from O₂ and NOT screened for CCHD:

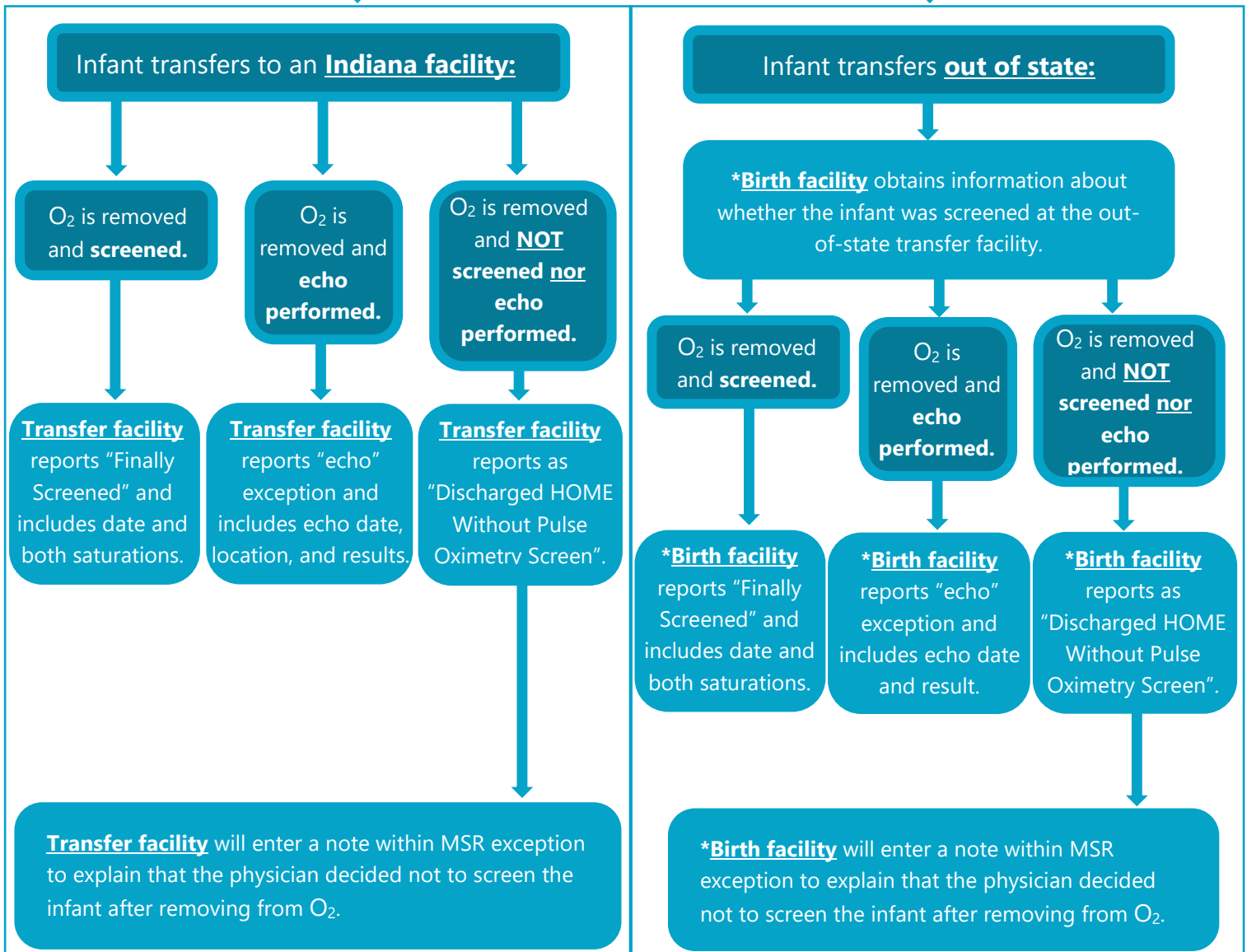
Birth facility reports infant as "Discharged HOME Without Pulse Oximetry Screen".

Birth facility enters note in exception that states the physician decided not to screen infant after removing O₂.

NBS Reporting Coordinator will review and close the case.

If infant is on supplemental oxygen and **TRANSFERS OUT** of the birth facility:

Birth facility always reports infant as “Transfer Out Without Screen” and adds a note stating “infant is on supplemental oxygen”.



The NBS Reporting Coordinator will then review all MSR exceptions and notes to close the case.

Infant TRANSFERS OUT before receiving heel stick or pulse oximetry (CCHD Screen):

IMPORTANT CLARIFICATION

Every infant who will be transferring out of the birth facility should have their initial heel stick and pulse oximetry (CCHD screen) performed **BEFORE** being transferred, **regardless of time after birth.**

Transfer out to an Indiana facility:

Birth facility reports MSR exception:

Report the infant as "transfer out without screen" exception for heel stick and/or pulse oximetry.

Transfer facility reports MSR exception:

Report the infant as "**finally screened**" and enter **all NBS information** in the MSR exception notes as soon as it is obtained.

Birth Facility obtains NBS results:

Obtain heel stick and pulse oximetry results from the **Indiana transfer facility** and document in the NBS log.

*Transfer out to an out-of-state facility

EFFECTIVE IMMEDIATELY

*Birth facility reports MSR exception:

Report the infant as "transfer out without screen" exception for heel stick and/or pulse oximetry.

*Birth facility obtains NBS results:

Obtain heel stick and pulse oximetry results from the **out-of-state transfer facility** and document in the NBS log.

*Birth facility reports MSR exception:

Infant is entered as a **NEW** exception as "**finally screened**" exception and enters **all NBS information** in the MSR exception notes as soon as it is obtained.

**The GNBS program understands that this process may not have been in place previously at many Indiana facilities. Please reach out to the GNBS program for assistance with establishing this procedure.*

Tips for Obtaining Out-of-State Newborn Screening Information

When calling and faxing requests to out-of-state facilities, state the reason behind why you need them to ensure timely communication:

"Per Indiana mandate, all newborn screening information for patients born in Indiana must be reported to the Indiana Department of Health. As an Indiana facility, we need this information to be able to submit the mandated reports."

Kentucky

Request heel stick results through the KY NBS Lab:

KY NBS State Lab:
Phone: 502-564-4446
Fax: 502-564-2905

Request pulse oximetry or echocardiogram results by calling the transfer facility directly.

Ohio

Request heel stick results through the OH NBS Program:

OH NBS Program:
Phone: 888-634-5227
Fax: 614-644-4648

Request pulse oximetry or echocardiogram results by calling the transfer facility directly.

Illinois

Request heel stick results by faxing a [Health Care Provider Consent and Authorization to Release Newborn Screening Results](#) form to the NBS Program:

IL NBS Program:
Phone: 217-785-8101
Fax: 217-557-5396

Request pulse oximetry or echocardiogram results by calling the transfer facility directly.

Michigan

Request heel stick results by faxing an [NBS Report Request Form](#) and your cover page to the NBS Program.

MI NBS Program
Phone: 517-335-4181
Fax: 517-335-9419 or 517-335-9739

Request pulse oximetry or echocardiogram results by calling the transfer facility directly.

Tennessee

Request heel stick results through the TN NBS Program:

TN NBS Program:
Phone: 615-532-8462
Fax: 615-532-8555

Request pulse oximetry or echocardiogram results by calling the transfer facility directly.

Wisconsin

Request heel stick results by faxing a [NBS Report Request Form](#) and your cover page to the WI State Lab:

WI State Laboratory of Hygiene
Phone: 608-262-6547
Fax: 608-262-5494

Request pulse oximetry or echocardiogram results by calling the WI SHINE personnel at 608-265-1894.